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Research demand signalling

National Learning Disability and Autism Programme

September 2022

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Foreword

In 2019, The NHS Long Term Plan committed to enabling people with a learning disability and autistic people to live happier, healthier, and longer lives. In response, NHS England formed their first National Autism Team within the pre-existing Learning Disability and Autism Programme to drive further improvements in the health outcomes of autistic people and people with a learning disability.

The National Learning Disability and Autism Programme works to reduce health inequalities experienced by people with a learning disability and autistic people by, for example, improving access to diagnoses and healthcare, increasing the use and quality of reasonable adjustments and increasing the quality, efficiency and effectiveness of healthcare provided. Some examples of this work include offering an annual health check for people with a learning disability, the development of an autism annual health check, conducting Learning from Lives and Deaths of people with a learning disability and autistic people (LeDeR) reviews and improving the quality of inpatient mental health care.

Health and social care policies focusing on improving the life chances of autistic people and people with a learning disability are not a new development. Policies have targeted improvements in this area with increasing regularity since, in the case of autism, the publication of The Autism Act (2009) which, in turn, prompted Adult Autism Strategies in 2010 and 2014 as well as a 2018 refresh to include a focus on improving life expectancy. The Adult Autism Strategy was replaced with an all-age autism strategy in 2021.

Similarly, policies targeting improvements in outcomes for people with a learning disability have been published with increasing regularity since, for example, the Transforming Care Programme, established in 2012, which aimed to improve health and care services to enable more people with a learning disability to live in their home community and with the right support. In 2015, Building the Right Support was published which aimed to improve community provision and reduce inappropriate hospital admissions.

For successive policies to deliver continuous and incremental improvements in outcomes they must be informed by high-quality and relevant evidence. While there

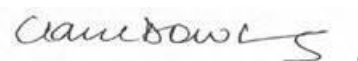
has been a welcome and rapid rise in the amount of learning disability and autism research conducted in recent years, investment has been slow to focus directly on addressing applied health and care questions with the highest likelihood of supporting delivery of policy ambitions.

In 2022, following the inclusion of learning disability and autism as priorities in the NHS Long Term Plan, a [five-year NHS autism research strategy for England](#) was published to ensure efforts toward policy ambitions are informed by the best available evidence. One commitment made in the autism research strategy was to identify pressing evidence gaps for service design and delivery and to communicate these gaps to the research community. This research demand signalling report is the first step in identifying areas which require more research focus and improving our ability to communicate these needs to the autism and learning disability research communities.

We are extremely grateful to the many people with lived experience, their families and carers, and professionals who have contributed to this report. Their contributions have been invaluable.



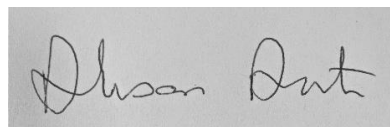
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Summary

The NHS Long Term Plan sets the priorities and ambitions of the NHS until the end of the decade. In some areas existing research evidence and clinical guidelines provide frameworks on which policy can be based, but in others, more research is required to inform policy decisions.

The NHS England Demand Signalling team developed the research demand signalling process to identify, prioritise and articulate the research questions that NHS services need answers to for them to deliver against the ambitions in the NHS Long Term Plan. The team brought together clinicians, academics, policy experts and people with lived experience from the learning disability and autism communities to identify the high priority areas for research. These are:

- **Annual health checks:** What makes health checks work well for people with a learning disability and for autistic people?
- **Improving quality of life:** What support (interventions) designed for autistic people, people with a learning disability, or both, improve their quality of life?
- **Support for people's mental health outside hospital settings:** What mental health support (interventions) can be provided outside mental health hospital settings?
- **Preventing and treating common illnesses:** What are the best ways of preventing or treating common illnesses in people with a learning disability or autistic people?
- **Outcomes that matter:** What measures should be used to determine if support (interventions) improves the outcomes that matter to autistic people and people with a learning disability?
- **Data innovation:** How can we make better use of data to meet the needs of autistic people and people with a learning disability?

This report presents the research questions we have identified through our demand signalling process, alongside the key evidence gaps. These will be used to influence research activity and funding calls.

NHS Long Term Plan ambitions

1. The [NHS Long Term Plan](#) has committed to improve learning disability and autism care across the NHS, including:

Reduce avoidable admissions <ul style="list-style-type: none">• More care to be provided in the community• Local providers to have more control over budgets• Autistic people and people with a learning disability to have a personal health budget	Improve quality of care <ul style="list-style-type: none">• All NHS commissioned care to meet learning disability improvement standards• Reduce length of admissions• Reduce use of seclusion and restrictive practice• Strengthen use of Care, Education and Treatment Reviews (CETRs)	Improve intensive and crisis support <ul style="list-style-type: none">• Develop specialist community teams• Ensure every area has a specialist seven-day multidisciplinary service• Provide more crisis support in the community and closer to home
Reduce avoidable deaths <ul style="list-style-type: none">• Increase uptake of the annual learning disability health check• Develop and pilot an autism health check• Reduce overuse of psychotropic medication for adults• Use learning from deaths reviews to improve services	Improve understanding <ul style="list-style-type: none">• Frontline staff to receive training• Add digital flag to health records to offer reasonable adjustments• Roll out learning disability improvement standards• Hearing, sight and dental checks for children and young people in residential special schools	Improve autism diagnosis <ul style="list-style-type: none">• Test innovations to reduce diagnostic waiting lists• Develop packages of support for autism and other developmental conditions• Provide a keyworker for children and young people with complex needs

2. So far, NHS England has:

- developed the annual health checks programme for people with a learning disability
- developed and trialled an autism-specific health check in primary care
- developed the LeDeR programme, publishing the LeDeR policy in May 2021, and annual LeDeR and Action from Learning reports

- significantly reduced the number of people with a learning disability and autistic people in a mental health inpatient setting
- developed, trialled and rolled out keyworkers for children and young people
- established the National Autism Programme
- developed a reasonable adjustments digital flag
- developed Care (Education) and Treatment reviews
- published [the learning disability improvement standards](#)
- launched a programme to support hearing, sight and dental checks for children and young people in residential schools.

Research demand signalling

3. Numerous methods have been widely adopted for the purposes of [priority setting](#), from the traditional [Delphi method](#) through to the more recently developed and increasingly popular [CHNRI method](#). All are systematic in nature and iterative in design, with an aim to build consensus and ownership among the community they serve. The method underpinning the research demand signalling process developed by the NHS England's Demand Signalling team is adapted from the Delphi method. It uses a series of workshops and evidence gathering to iteratively refine areas for research of unmet need (see [Annex](#)). The Demand Signalling team led the process, working in partnership with the National Clinical Director for Learning Disability and Autism and the NHS England Learning Disability and Autism Policy Team.
5. Senior stakeholders from a range of professional backgrounds and those with lived experience identified and prioritised six high-level areas for research to meet the NHS Long Term Plan objectives.
6. The evidence was then reviewed, followed by further stakeholder engagement to develop detailed research questions in areas of unmet need.
7. By following this iterative process and involving representatives from across the learning disabilities and autism communities, the agreed outputs can be mapped back to the relevant NHS Long Term Plan ambitions.

1. Health checks

Table 1: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
What makes annual health checks work well for people with a learning disability and for autistic people?	<p>Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people. To help do so, we will improve uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, so that at least 75% of those eligible have a health check each year.</p> <p>We will also pilot the introduction of a specific health check for people with autism, and if successful, extend it more widely.</p>

Detailed considerations

- Annual health checks are intended to help reduce the health inequalities experienced by people with a learning disability and autistic people. The inequalities include differences in health status, life expectancy, access to healthcare and wider determinants of health (eg socioeconomic status, quality housing and health-related behaviour). For many, the COVID-19 pandemic may have made accessing healthcare even harder.
- The NHS Long Term Plan committed to ensuring that 75% of people aged over 14 years on a GP learning disability register have an annual health check. Based on evidence¹ that annual learning disability health checks identify previously unmet health needs for people with a learning disability, people with a learning disability should be offered these annually. In 2020/21 despite the COVID-19 pandemic, GPs offered health checks to nearly three-quarters of people on learning disability registers. However, as many people with a learning disability are not known to their GP, the proportion of this population being offered a health check will be much smaller.
- The development and testing of an annual health check for autistic people was prioritised at a collaborative summit run by Autistica in late 2017. That check has now been co-produced with autistic people and primary care

professionals. A randomised controlled trial of the health check for autistic people, funded by Autistica and NHS England, started in 2021.

- We need to understand how to increase the uptake, quality and consistency of health checks for both groups of people, as well as make them more accessible to groups who may find them harder to access (eg people in contact with the criminal justice system, people in residential care, homeless people, people from ethnic minorities, people living in poverty, young people). Further, we need to understand what the best delivery model is for health checks (eg in primary care or other settings, via telemedicine or face to face, as well as which professionals should be involved) and the impact this has on patient outcomes, equitable uptake, cost-effectiveness and ensuring these are streamlined with health action plans.

¹ Kennedy N, Kennedy J, Kerr M et al. (2022) Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales, UK. *BMJ Open* doi: [10.1136/bmjopen-2021-049441](https://doi.org/10.1136/bmjopen-2021-049441)

2. Improving quality of life

Table 2: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
What support (interventions) that are designed for autistic people, people with a learning disability, or both improve quality of life?	<p>The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing.</p>
	<p>Increased investment in intensive, crisis and forensic community support will also enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services.</p>
	<p>Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives. To move more care to the community, we will support local systems to take greater control over how budgets are managed. Drawing on learning from the new care models in tertiary mental health services, local providers will be able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out-of-area placements.</p>

Detailed considerations

- There is an urgent research need to develop evidence-based, needs-led, post-diagnostic support services for autistic people and people with learning disability and their families. Here the focus is on support (interventions) designed specifically to help autistic people or people with a learning disability live happier, healthier and longer lives, as opposed to testing/adapting existing therapies for health conditions among autistic people and people with a learning disability (covered in priority area 4).
- **What interventions are we interested in?** The mechanism of action and intent of autism interventions is much debated.² It is important that the intended purposes of interventions are carefully selected and sensitive to

community priorities. Interventions must not only be assessed for effectiveness but also acceptability to autistic people. Interventions should not seek to explicitly treat or repress being autistic or having a learning disability. Instead they should address specific issues that are recognised to cause people difficulty, distress or limit their life opportunities. Examples are: improving life skills, helping to cope with uncertainty, developing communication skills, developing safe eating, sleeping or exercise habits, increasing autonomy, sensory issues, building on strengths, reducing stigma from others, helping people break down overwhelming tasks, preventing burnout.

- **What outcomes are we interested in improving?** Interventions should focus on improving outcomes that autistic people, people with a learning disability and carers/families say are important to them. Foundational work, like the International Classification of Functioning Disability and Health (ICF) (a list of the issues that can be enabling or disabling for people) for which a set of [autism core sets](#) were developed, [community research prioritisations](#) and [quality of life measures for autistic people](#) could be used to help identify appropriate outcomes for intervention.

² Leadbitter K, Buckle KL, Ellis C, Decker M (2021) Autistic self-advocacy and the neurodiversity movement: implications for autism early intervention research and practice. *Front Psychol* <https://doi.org/10.3389/fpsyg.2021.635690>

3. Support for mental health outside hospital settings

Table 3: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
<p>What mental health support can be provided outside of hospital settings to reduce reliance on inpatient mental healthcare?</p>	<p>Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives. Drawing on learning from the new care models in tertiary mental health services, local providers will be able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out-of-area placements. By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. For children and young people, no more than 12 to 15 children with a learning disability, autism or both per million, will be cared for in an inpatient service.</p> <p>Increased investment in intensive, crisis and forensic community support will also enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services. Every local health system will be expected to use some of this growing community health services investment to have a seven-day specialist multidisciplinary service and crisis care. We will continue to work with partners to develop specialist community teams for children and young people, such as the Ealing Model, which has evidenced that an intensive support approach prevents children being admitted into institutional care.</p>

Detailed considerations

- Anecdotally we have heard that the availability, quality and effectiveness of mental health support in the community for autistic people and people with a

learning disability vary widely across the country. Many national and regional initiatives have been launched to increase the proportion of mental healthcare provided in the community and outside hospital settings. Below are some detailed questions that must be answered to increase the availability of effective community support.

- **People with a learning disability** – research is needed into which models of community support, including those provided by both health and adult social care services, are acceptable to people with a learning disability and effective at safeguarding their health and wellbeing and consequently their quality of life.
- **Autistic people without a learning disability** – access to health or social care support outside specialist inpatient settings must be improved to provide appropriate alternatives to inpatient care. Research is needed to test the acceptability, feasibility and effectiveness of community models of care for treating and supporting people in a mental health crisis. Interventions need to be designed and evaluated to identify and support people before they become extremely unwell and prevent them from reaching crisis. Evidence is needed for the effectiveness of stepped care models in allowing clinicians to respond to and offer low to high intensity support to people as their needs change over time. More research is needed into the use of risk assessment protocols to determine when inpatient care is appropriate, and to determine how best to support autistic people when they transition between services (e.g. child to adult, community to inpatient) while minimising any negative consequences of this.
- There is inadequate evidence for the care provided to autistic people in inpatient settings or those at risk of requiring inpatient mental healthcare. Evidence is needed for the effectiveness and long-term safety of interventions and strategies designed to reduce distress (e.g. positive behaviour support), transition people out of long-term inpatient settings and to remove people from long-term segregation within inpatient settings.

4. Preventing and treating common illnesses

Table 4: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
What are the best ways of preventing or treating illnesses that people with a learning disability or autistic people often get?	Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people. And we will continue to fund the Learning from Lives and Deaths Review Programme (LeDeR), the first national programme aiming to make improvements to the lives of people with learning disabilities.

Detailed considerations

- Some physical, mental and neurological health conditions commonly co-occur in autistic people and people with a learning disability. However, research trials into the prevention, treatment or management of these conditions often excludes people with a learning disability and autistic people from trials – meaning we do not always know if they are safe and effective in these groups. Therefore, research is needed both to understand the safety and efficacy of these treatments in autistic people and people with a learning disability and to explore models of research design that would better include them. If current evidenced-based treatments are not safe and/or effective in these groups, how can they be adapted or what new approaches are needed?
- Interventions can include (but are not limited to): talking therapies (like cognitive behavioural therapy), pharmacological (drug) approaches, low intensity support (like social prescribing), environmental or lifestyle changes (like diet management), etc.

5. Outcomes that matter

Table 5: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
What measures should be used to determine if a support (intervention) improves outcomes that matter to autistic people and people with a learning disability?	The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing.

Detailed considerations

- Research is needed to better understand which outcomes are important to autistic people and people with a learning disability, as well as their families and carers. They need to be asked to ensure they are offered person-centred healthcare, to be supported to develop goals for the issues that matter to them.
- Standardised measures need to be developed for these outcomes, so that interventions can be developed which will improve outcomes that matter to autistic people and people with a learning disability. What matters most will be individual and differ from person to person this needs to be reflected in the number of outcomes measured and flexibility in how an outcome is measured.
- The outcomes could be focused on a range of topics, such as improving quality of life, improving health and fitness, people being more in control of their healthcare and reducing anxiety and distress.

6. Data innovation

Table 6: Summary of outputs from the demand signalling process alongside their relevant NHS Long Term Plan commitment

Research theme	NHS Long Term Plan ambition
How can we make better use of data to meet the needs of autistic people and people with a learning disability?	The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing. Over the next five years, national learning disability improvement standards will be implemented and will apply to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families. By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism. We will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.

Detailed considerations

- NHS datasets record data about the care people receive. These are sometimes referred to as 'routinely collected', 'point-of-care' or 'observational' data sources. Typically, these are used for clinical, financial and administrative purposes. However, with the correct information governance, ethics and data quality assurances in place, these data sources could be used for research or quality improvement.
- We are particularly interested in understanding the current barriers to collecting high-quality data through NHS datasets, and armed with this, facilitate data collection and linkage to allow us to better monitor outcomes for people with a learning disability and autistic people. Barriers to collecting data and system operability are a well-recognised problem across the system and are thus an overarching priority to address at NHS England. This data can also be used to identify practices that are working well in one place and could be shared throughout the system. One challenge is the definition and/or identification of autistic people within such datasets, and the mismatch in

numbers when different methods are used. Further work is required to explore and improve the reliability of definitions.

- We would additionally be interested in research into linkages of routine data sources from different settings, to improve understanding of what the issues are with regards to data linkage. Research findings that demonstrate variation in access to care, the type of care provided, or outcomes from care would be a powerful lever for quality improvement programmes.

Next steps

8. This document has outlined the systematic approach to identification and prioritisation of research questions and articulates the outputs for learning disabilities and autism services in England. The next stage is to undertake a signalling campaign, targeting and tailoring the signals according to audience; this work is being led by NHS England's Demand Signalling team.
9. There are four distinct communities for whom this work is relevant or of interest: those with lived experience of learning disability and autistic people, those who are conducting research in this field, those who fund studies related in this field and those who design system policy.
10. People with lived experience were involved in all stages of this demand signalling process. We will use existing channels with research funders to further disseminate and raise awareness of this report, and will work with royal colleges (such as the Royal College of Paediatrics and Child Health, Royal College of General Practitioners, Royal College of Speech and Language Therapists, Royal College of Occupational Therapists) and charities such as Autistica, the National Autistic Society and Ambitious about Autism to enhance the signal. We will also engage directly with autism and learning disability researchers.
11. Signalling to researchers and innovators will be targeted through a wide range of National Institute for Health Research (NIHR) programmes, UK Research and Innovation (UKRI) and online portals, such as the Accelerated Access Collaborative (AAC) Innovation Service.

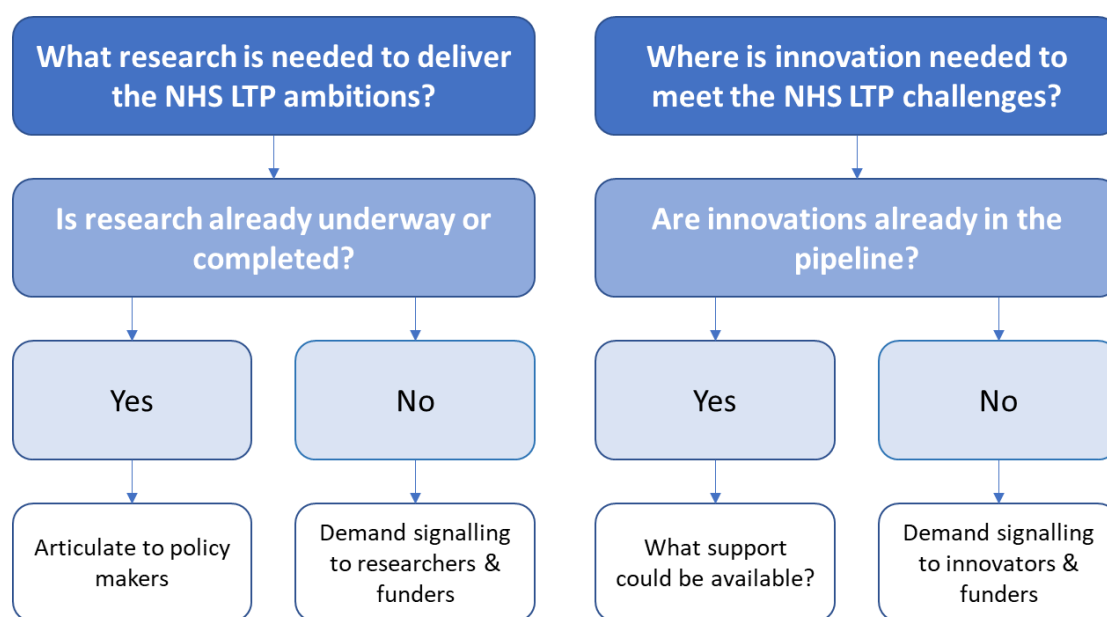
12. With regard to funders, for areas where relevant research is ongoing, the Demand Signalling team will work with the NIHR and UKRI to establish a route for getting the latest evidence to policymakers in a timely manner. We will flag the better use of existing and emerging evidence as an area that could be vastly improved.
13. For funding calls that are already in development but could potentially be aligned, the Demand Signalling team will encourage funders to tailor their calls accordingly, be that as a highlight note as part of the call, or as reference material to better inform decision-making at selection and funding committees.
14. For priority areas that are underserved, and evidence is lacking, the Demand Signalling team will work closely with funders to design bespoke calls or programmes.
15. Progress and impact will be tracked and monitored, with the aim of establishing a bi-directional feedback loop between the NHS England National Learning Disability and Autism Programme, the funders and the research community.

Annex: Methodology

Research generates new knowledge and guides best practice. Innovation explores different ways of doing things to improve the quality of care provided to patients.

Demand signalling is the process of characterising the research questions and making researchers and funders aware of them. A separate process will be developed to understand and signal the innovation challenges that link to the NHS Long Term Plan. The final stage of demand signalling is the use of commercial and policy levers to realise the benefits of research and innovation for the NHS (Figure A1.1).

Figure A1.1: Aims of research and innovation demand signalling



The research demand signalling process developed by the NHS England Demand Signalling team involves stakeholders from across the health and care system including: the national clinical director, policy leads, clinical leads, allied health professionals, analysts, leading academics, charities and people with lived experience.

Workshop

Through targeted engagement with senior-level strategic stakeholders from across a range of organisations, the objective of the workshop was to determine and agree the high-level priority areas where more research is needed to deliver against the ambitions for learning disabilities and autism in England, as is outlined in the NHS Long Term Plan (see NHS Long Term Plan ambitions for Learning Disabilities and Autism).

Facilitated by the Demand Signalling team, 17 senior stakeholders from a range of professional backgrounds and those with lived experience identified six high-level priority areas for research.

Additionally, the NIHR Innovation Observatory (NIHR IO) carried out a horizon scan to identify any innovations in the pipeline that may meet the needs identified in the workshop. This primarily focused on learning disabilities and demonstrated the challenges of scanning for a condition where pharmacological or medical device interventions have less prominence.

NHS England lived expert group

The [NHS England Learning Disability and Autism Advisory Group](#), a team of experts by experience, work in partnership with NHS England to help us shape solutions around learning disability and autism. It is made up of 15 people with a learning disability, autistic people and family carers. They aim to make a difference to the NHS by making their voices heard, promoting equity and inspiring better involvement.

Roundtable

The Demand Signalling team assembled a roundtable. 27 people were invited and attendees were provided with evidence summaries for each of the high-level priority areas.

The objective of the roundtable was to bring clinicians, academics and those with lived experience together to discuss the identified areas of research, build

consensus, and further refine the list of priorities, such that this could be used as a guide to formulate researchable questions.

Where a research question was a comment about service delivery, the relevant NHS England teams were notified.

By following this iterative process, involving a breadth of representatives from across the learning disabilities and autism communities, the agreed outputs from the roundtable can be mapped back to the relevant NHS Long Term Plan ambitions.

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